

**Opening Statement
Chairman Mark Souder**

**“Federal Health Programs and Those Who Cannot Care for
Themselves: What Are Their Rights, and Our Responsibilities?”**

**Subcommittee on Criminal Justice, Drug Policy, and Human Resources
Committee on Government Reform**

April 19, 2005

Good afternoon and thank you all for being here for this important hearing. A special thank you to our witnesses, as well, some of whom have traveled a great distance and all of whom are giving us the benefit of their knowledge and experience today.

The hearing today is “Federal Health Programs and Those Who Cannot Care for Themselves: What are Their Rights and Our Responsibilities.” We hope to examine the support provided by federal Medicaid and Medicare programs for ordinary care of incapacitated citizens who are not in the dying process.

The people we are talking about, as incapacitated citizens, cannot speak for themselves, and cannot care for themselves. They necessarily require the long term care of family, community or institutions to live. Although there are provisions within Medicaid and Medicare that address advance medical directives of such individuals, the provisions do not address many issues surrounding the ordinary care of incapacitated individuals.

These are issues that have been raised in light of the tragic Terri Schiavo situation, and which now deserve our focused attention and exploration.

First among these issues is whether, in the absence some sort of advance medical directive or express medical power of attorney, there should be a *federal presumption in favor of life*, so that a Medicare or Medicaid patient who is incapacitated is not denied ordinary care such as hydration or nutrition without due process, and full exercise of their rights as human beings, despite their incapacity.

This is our point of departure, and although we may leave here with more questions than answers today, it’s important to examine what types of treatment options are available for incapacitated citizens who are not in the dying process; whether the various legal instruments – such as advance medical directives or medical powers of attorney – are sufficient; and what protections exist for incapacitated individuals to ensure that their constitutional rights of due process are met.

At a minimum, our federal programs should protect patients rather than pave the way to hasten their death, but we do not have a federal presumption where a person’s wishes are unknown and unknowable. This creates a vacuum where someone else may determine that a patient’s life is one not worth living, and this is most definitely a slippery slope. Let me quote at

length a homily given by Archbishop Galen, which underlines the importance of staying vigilant against new developments in the law that run counter to a Judeo-Christian understanding of human dignity:

If you establish and apply the principle that you can 'kill' unproductive human beings, then woe betide us all when we become old and frail! If one is allowed to kill unproductive people, then woe betide the invalids who have used up, sacrificed and lost their health and strength in the productive process... Poor people, sick people, unproductive people, so what? Have they somehow forfeited the right to live? Do you, do I, have the right to live only as long as we are productive? ... Nobody would be safe anymore. Who could trust his physician? It is inconceivable what depraved conduct, what suspicion would enter family life if this terrible doctrine is tolerated, adopted, carried out.

Archbishop Clemens von Galen was not speaking out as a consequence of the Terri Schiavo controversy – he anticipated it. Archbishop Clemens von Galen spoke these words from the pulpit on August 3, 1941 against a euthanasia program being instituted by the German government. The sermon was aimed at a specific policy in a specific place and time, but he touched upon a recurrent theme that transcends place and time. It is a helpful warning from history, to guide our footsteps on our uncertain, post-Schiavo, path.

We have a variety of witnesses joining us today to help draw out some of these important issues. Our first panel consists of Representative Dave Weldon, of the 15th district of Florida. Congressman Weldon is an esteemed former member of the Government Reform committee, and former Chairman of the Census Subcommittee. Congressman Weldon is also a medical doctor, and brings his unique perspective and experience on federal health care matters to this hearing today.

Our second panel consists of Dr. Donald A. Young, the Deputy Assistant Secretary for Planning and Evaluation at Health and Human Services, who in his medical practice has first hand experience with end of life care.

Our third and final panel consists of four witnesses: Diane Coleman, President and Founder of a disability rights advocacy group called Not Dead Yet.

Bob Sedlmeyer, from my Congressional district in Indiana. Bob has a nineteen year-old daughter, Valerie, who has been incapacitated since birth, and for whom Bob and his wife provide in-home care.

Kate Adamson, who had a severe stroke and experienced what is known as “locked-in syndrome.” Although she was conscious and aware, she was physically totally unresponsive, and at one point her doctors withdrew all nutrition and hydration from her.

And Professor Robert Destro, from the Columbus School of Law of Catholic University. He served for six years as a commissioner on the United States Commission on Civil Rights, and led the Commission’s discussions in the areas of discrimination on the basis of disability.